Federal Privacy Laws: Guidance and Resources for State and Local Agencies Exploring Secondary Uses of Data

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Introduction

Advances in data analytics have increased interest in leveraging existing administrative data for socially beneficial uses, such as furthering social science or public health applications. However, using existing administrative data raises important ethical and legal issues, especially when the data contains identifying and sensitive information. Thus, understanding the myriad of federal laws that govern the collection, use and release of information is important for any organization seeking to access and use administrative data for socially beneficial uses.

The federal government regulates the collection and use of data in a variety of contexts. Federal agencies administer many programs that create or collect data. Federal laws, such as the Privacy Act of 1974, regulate the use of data by these federal agencies. The federal government also funds programs administered by state, local, and non-governmental organizations. As a condition for receiving federal funds, laws frequently require these organizations to implement specific protections for data collected or created as part of the federal program. For some datasets and programs, federal laws provide a uniform national standard for protecting information. For other datasets and programs, federal laws might permit state and local governments or private organizations to implement more stringent protections for information.

Because of these various federal approaches to data protection, it is often difficult to understand the specific legal protections for a given dataset. This annotated resource compilation is intended to help state and local agencies access information and resources needed to better understand the federal legal protections and requirements associated with datasets collected by federal agencies or as part of a federally funded program.

Federal Laws

Family Educational Rights and Privacy Act

Keywords: Education

Legal Basis

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<td>20 U.S.C. § 1232g</td>
<td>34 C.F.R. Part 99</td>
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Federal Resources

- The US Department of Education website provides guidance and resources relating the privacy of education records.
- The Family Policy Compliance Office within the Department of Education provides resources and information, including answers to Frequently Asked Questions (FAQs) and guidance for parents, students, and school officials.
- Department of Education maintains a library of privacy resources for various topics and audiences. The resources include:
  - Online trainings, including Student Privacy 101, and Integrated Data Systems and Student Privacy.
  - Model forms and notices to assist state and local education agencies comply with FERPA requirements.
  - A checklist for creating written agreements
  - Security best practices
  - Best practices for state education agency websites
  - A summary of FERPA disclosure exceptions
  - Information on Integrated Data Systems

Theme: Education

These laws protect and regulate data that are collected and used by federally funded, sponsored, or operated programs relating to education.
• The Office of the Chief Privacy Officer within the Department of Education implements FERPA and PPRA. This website contains notices to state and local educational agencies regarding their responsibilities under these laws and provides model forms and notices that can be adapted and used to fulfill legal requirements.
• The FERPA/IDEA Cross-Walk provides side-by-side comparisons of the legal requirements of FERPA, and IDEA Parts B & C.
• This webinar and related materials provide information on data sharing between schools and child welfare agencies regarding foster children.
• The Building Capacity to Use Linked Data for Program Improvement and Research Initiatives, funded by the Department of Health and Human Services, provides resources, case studies, and planning guides to facilitate linking administrative data to support data analytics aimed at benefiting early care and education programs.

Protection of Pupil Rights Amendment

Keywords: Education

Federal Resources

• This federal resource provides a summary of PPRA requirements.
• The Department of Education website provides model notices to inform individuals of their rights under PPRA and provides model notice, consent, and opt-out forms for school activities regulated by PPRA.
• This federal summary provides a brief overview of the eight areas protected by the PPRA.
• The Office of the Chief Privacy Officer within the Department of Education implements FERPA and PPRA. This website contains notices to state and local educational agencies regarding their responsibilities under these laws and provides model forms and notices that can be adapted and used to fulfill legal requirements.
• This federal guidance summarizes the policies that local education agencies must adopt to comply with PPRA.

Individuals with Disabilities Education Act Part B and Part C

Keywords: Education

Federal Resources

• The US Department of Education provides guidance and resources relating the privacy of education records at studentprivacy.ed.gov.
• This FAQ provides guidance for common questions relating to confidentiality requirements contained in IDEA, including details relating to parental consent requirements and exceptions.
• The FERPA/IDEA Cross-Walk provides side-by-side comparisons of the legal requirement of FERPA, and the IDEA Part B and C regulations.
Higher Education Act (National Student Loan Data System)

Keywords: Education

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<td>20 U.S.C. § 1092b</td>
<td>34 C.F.R. Part 5b</td>
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Federal Resources

- The NSLDS Privacy Impact Assessment contains detailed information about the nature of the information contained in the NSLDS, specific authorized uses of NSLDS data, and the conditions for sharing NSLDS data.
- The Department of Education provides limited access to NSLDS data to authorized uses through this secured portal.
- This federal website provides guidance for obtaining access to NSLDS data, including particularized information for specific types of NSLDS users and regular NSLDS newsletters.
- Limited NSLDS information and aggregate data can be accessed and downloaded from the data.gov website.
- The Department of Education provides certification form templates for NSLDS access requests by state grant agencies or guaranty agencies.

New Head Start Program Performance Standards

Keywords: Education; Social Service Programs

Legal Basis

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<td>42 U.S.C. § 9801, et seq.</td>
<td>45 C.F.R. § 1303, Subpart C</td>
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Federal Resources

- The Department of Health and Human Services website contains information on Head Start regulations and policies, including program standards that are intended to encourage the use of Head Start data.
- The Administration for Children & Families, which administers the Head Start Program, created a general fact sheet for the Head Start Program Performance Standards. The fact sheet describes the ways that the final rule facilitates the use of data to improve Head Start Programs. Additionally, the Administration for Children & Families created a FAQ to address specific questions related to the final rule.
- The Building Capacity to Use Linked Data for Program Improvement and Research Initiatives, funded by the Department of Health and Human Services, provides resources, case studies, and planning guides to facilitate linking administrative data to support data analytics aimed at benefiting early care and education programs.
- The Department of Health and Human Services provides resources, information, and guidance relating to the Head Start Program Performance Standards on its website.
- The final rule for Head Start Program Performance Standards outlines the legal requirements for the Head Start Program, including privacy protections for child records.
US Department of Health and Human Services
Privacy Act Regulations

Keywords: Federal Health Plans; Social Service Programs

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Federal Resources

- The Department of Justice compiled an [extensive online treatise](#) outlining the general requirements of the Privacy Act of 1974. The Department of Justice treatise includes detailed description of court cases and opinions interpreting the federal Privacy Act statute.
- The [Department of Health and Human Services website](#) contains information, resources, and guidance relating to the implementation of the federal statute within the department.
- The website includes links to the Department’s [System of Records Notices](#), which provide public notice of the information that the department collects and the permitted purposes for using or disclosing information within a system of records.
- The website also provides links to the Department’s [Privacy Impact Statements](#), which evaluate the privacy protections for systems that collect personally identifiable information.

Medicaid Applicant and Beneficiary Information Safeguards

Keywords: Federal Health Plans

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<td>42 C.F.R. Part 431, Subpart F</td>
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Federal Resources

- The Centers for Medicare and Medicaid Services provides information and resources relating to training, privacy impact statements, and program guidance on its [website](#).
- The Centers for Medicare and Medicaid Services [Information Systems Security and Privacy Policy](#) describes the specific policies and practices for all users of the Centers for Medicare and Medicaid Services data systems.
- [This issue brief](#) from the Medicaid Innovation Accelerator Program provides guidance on privacy, data use, and developing data use agreements. The issue brief contains links to data use agreement best practices and state examples of data use agreements.
- In this [letter to state Medicaid officials](#), the Health Care Financing Administration, the Health Resources and Services Administration and The Centers for Disease Control and Prevention announce an interagency agreement to facilitate collaboration and data sharing and provide a model data sharing agreement for state Medicaid and health agencies.
Population Research and Voluntary Family Planning Programs (Title X)

Keywords: Social Service Programs

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<td>42 C.F.R. Part 59, Subpart A</td>
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Federal Resources

- The [Department of Health and Human Services website](#) provides links to information and guidance concerning Title X grants, requirements and policies.
- The Office of Population Affairs, which administers Title X, issued this [Program Policy Notice](#) to provide specific guidance relating to confidentiality requirements for Title X services to adolescents.
- The [Program Guidelines for Grants for Family Planning Services](#) provides Title X grantees guidance for management and administration of family planning services. The guidelines contain information on Title X legal requirements, including confidentiality of client records.

The Supplemental Nutrition Assistance Program (SNAP) Confidentiality Provisions

Keywords: Social Service Programs

Legal Basis

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<td>7 C.F.R. § 272.1</td>
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Federal Resources

- The [SNAP Document Library](#) contains links to tools and resources related to SNAP administration.
- [SNAP-Ed Connection](#) is a resource for State and local personnel providing SNAP education relating to nutrition and obesity prevention.
- [This 2014 resource](#) created by the Administration for Children and Families makes a case for sharing administrative data from different federal data systems, including SNAP. The document provides information on applicable federal legislation and provides strategies for implementation.


Keywords: Social Service Programs

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Federal Resources

- The Food Service Administration [website](#) contains information links to the statutes and regulations pertaining to the WIC program.
WIC State agencies are sometimes asked to support efforts to manage public health risks. This 2014 federal guidance document addresses WIC confidentiality requirements as they relate to compliance with screening protocols recommended by the Centers for Disease Control and Prevention.


Keywords: Social Service Programs

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Federal Resources

- The Food and Nutrition Service website provides general information on the National School Lunch Program and the School Breakfast Program, including links to regulations and guidance.
- The Food and Nutrition Service provides specific guidance to relating to the disclosure requirements for the various child nutrition programs.
- The 2017 Eligibility Manual for School Meals contains detailed information and guidance on the confidentiality and disclosure requirements of the federal nutrition assistance programs, including National School Lunch Program Special Milk Program for Children, School Breakfast Program, Summer Food Service Program, and Child and Adult Care Food Program. The manual includes a useful chart summarizing the specific requirements to disclose information to various recipient organizations.
- The federal Food and Nutrition Service provides prototype household notice, consent and program application forms.

Special Milk Program Confidentiality Provisions

Keywords: Social Service Programs

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Federal Resources

- The Special Milk Program website provides general information on the Special Milk Program, including links to regulations and guidance.
- The Food and Nutrition Service provides specific guidance to relating to the disclosure requirements for the various child nutrition programs.
- The 2017 Eligibility Manual for School Meals contains detailed information and guidance on the confidentiality and disclosure requirements of the federal nutrition assistance programs, including National School Lunch Program Special Milk Program for Children, School Breakfast Program, Summer Food Service Program, and Child and Adult Care Food Program. The manual includes a useful chart summarizing the specific requirements to disclose information to various recipient organizations.
for Children, School Breakfast Program, Summer Food Service Program, and Child and Adult Care Food Program. The manual includes a useful chart summarizing the specific requirements to disclose information to various recipient organizations.

- The federal Food and Nutrition Service provides prototype household notice, consent and program application forms.

Summer Food Service Program Confidentiality Provisions

Keywords: Social Service Programs

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<td>7 C.F.R. § 225.2; 7 C.F.R. § 225.15</td>
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Federal Resources

- The Summer Food Service Program website provides general information on Summer Food Service Program, including links to regulations and guidance.
- The Food and Nutrition Service provides specific guidance to relating to the disclosure requirements for the various child nutrition programs.
- The 2017 Eligibility Manual for School Meals contains detailed information and guidance on the confidentiality and disclosure requirements of the federal nutrition assistance programs, including National School Lunch Program Special Milk Program for Children, School Breakfast Program, Summer Food Service Program, and Child and Adult Care Food Program. The manual includes a useful chart summarizing the specific requirements to disclose information to various recipient organizations.
- The federal Food and Nutrition Service provides prototype household notice, consent and program application forms.

Child and Adult Care Food Program (CACFP) Confidentiality Provisions

Keywords: Social Service Programs

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Federal Resources

- The Child and Adult Care Food Program website provides general information and resources on the Child and Adult Care Food Program, including links to regulations and guidance.
- This 2015 guidance from the Food and Nutrition Service describes the disclosure requirements for several federal nutrition programs, including the Special Milk Program for Children, Summer Food Service Program, Child and Adult Care Food Program, National School Lunch and School Breakfast Programs.
- The 2017 Eligibility Manual for Child Nutrition Programs contains a section outlining the confidentiality requirements under the National School Lunch Act. The manual contains a useful chart detailing when consent is required for disclosures under various circumstances and prototype data sharing agreements.
- The federal Food and Nutrition Service provides prototype household notice, consent and program application forms.
Homeless Management Information System (HMIS)

Keywords: Social Service Programs

Legal Basis

**Federal Resources**

- The [Data and Technical Standards Final Notice](#) establishes the baseline privacy and security standards for Homeless Management Information Systems (HMIS).
- The Department of Housing and Urban Development [website](#) provides information, guides and tools for Continuums of Care, HMIS agencies and administrators, HMIS users, and HMIS vendors to assist in HMIS implantation and ongoing operation. The guides and tools include manuals for various Housing and Urban Development programs that utilize an HMIS.
- The [Housing and Urban Development website](#) contains information and guidance relating to HMIS regulations.
- The [HMIS 101 training](#) provides in-depth information for new program grantees and staff relating to the implementation and operation of an HMIS, including considerations and requirements relating to privacy, confidentiality, and security. The training materials include summaries of policy solutions for issues relating to privacy, confidentiality, and consent.

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**SAMHSA: Confidentiality of Substance Abuse Patient Records**

Keywords: Substance Abuse

Legal Basis

**Federal Resources**

- This [final rule](#) updates and modernizes regulations protecting the confidentiality of alcohol and drug abuse patient records. The final rule contains a description of regulatory changes and justifications.
- This [final rule](#) addresses the prohibition on re-disclosure notice and circumstances under which lawful holders may use and disclose patient identifying information for purposes of payment, health care operations, and audits and evaluations.
- This [fact sheet](#) explains a 42 CFR Part 2 Program and how healthcare providers can determine how Part 2 applies to them.
- This [fact sheet](#) describes how 42 CFR Part 2 applies to the electronic exchange of healthcare records with a Part 2 Program.
- This [FAQ](#) provides specific guidance for issues relating to substance abuse patient records, including issues of consent, emergency disclosures, and re-disclosure.
- Health Information Exchange (HIE) organizations facilitate the exchange between health care providers and other organizations. This [FAQ](#) addresses the unique issues associated with applying the Substance Abuse Confidentiality Regulations to HIEs.
• Many organizations covered by the Substance Abuse Confidentiality Regulations as well as the Health Insurance Portability and Accountability Act rules and regulations. This federal resource describes how to apply these two regulatory frameworks.

Non-Federal Resources
• This prospective piece in the New England Journal of Medicine discusses the impact of the SAMHSA Confidentiality provisions on substance abuse research.

The VA Claims Confidentiality Statute
Keywords: Veterans; Federal Health Plans

Legal Basis

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<td>38 U.S.C. § 5701</td>
<td>38 C.F.R. §§ 1.500-1.527</td>
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Federal Resources
• Veterans Health Administration Directive 1605.01 provides specific guidance for the release of information protected by various federal laws, including the Privacy Act of 1974, the Health Insurance Portability and Accountability Act, the VA Claims Confidentiality Statute, the Confidentiality of Medical Quality Assurance Review Records, and Confidentiality of Drug Abuse, Alcoholism and Alcohol Abuse, Human Immunodeficiency Virus (HIV) Infection, and Sickle Cell Anemia Medical Records.
• There are many ethical issues associated with the privacy and confidentiality of VA records. The VA has compiled a list of resources exploring some of these ethical issues here.

Non-Federal Resources
• This issue brief was created by the Network for Public Health Law to provide background on the various legal issues associated with the disclosures of identifiable VA information for public health purposes.

Confidentiality of Drug Abuse, Alcoholism and Alcohol Abuse, Human Immunodeficiency Virus (HIV) Infection, and Sickle Cell Anemia Medical Records
Keywords: Veterans; Substance Abuse

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Federal Resources
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• This FAQ addresses issues associated with the confidentiality of HIV test results held by the VA.
• There are many ethical issues associated with the privacy and confidentiality of VA records. The VA has compiled a list of resources exploring some of these ethical issues here.

Non-Federal Resources
• This issue brief was created by the Network for Public Health Law to provide background on the various legal issues associated with the disclosures of identifiable VA information for public health purposes.

Confidentiality of Medical Quality Assurance Review Records

Keywords: Veterans

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Appendix A

Themes

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SUPPORTERS

The Network for Public Health Law is a national initiative of the Robert Wood Johnson Foundation.

This document was developed by Cason Schmit, Research Assistant Professor, Texas A&M University and reviewed by Jennifer Bernstein, Deputy Director, Mid-States Region of The Network for Public Health Law. The Network for Public Health Law provides information and technical assistance on issues related to public health. The legal information and assistance provided in this document does not constitute legal advice or legal representation. For legal advice, please consult specific legal counsel.